

ICU

I s s u e s &
A n s w e r s

Palliative Care for Children

How it can improve
your child's quality of
life and reduce your
child's suffering.

Society of
Critical Care Medicine

The Intensive Care Professionals

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Understanding Palliative Care for Children

What Is Palliative Care?

- Palliative care is treatment given by trained specialists to improve quality of life and reduce suffering of children with life-threatening or life-limiting medical conditions. This specialized care is provided along with usual medical treatments or when these treatments cannot improve or cure your child's condition. Palliative care can also be given to children who are suffering from severe symptoms of chronic disease. Palliative care seeks to relieve physical, social, emotional, and spiritual suffering that your child and family may have.
- Palliative care aims to make your child comfortable and limit procedures and tests when possible. While all of your child's doctors and nurses will try to prevent discomfort, treatments offered by the palliative care team are further designed to control or stop any uncomfortable symptoms. New or different medications and therapies may be started to make your child more comfortable and procedures less painful.

- Palliative care includes clear and thoughtful communication with families. You can be involved as much as you like as treatment decisions are made for your child. This approach ensures that you and your family's concerns are addressed by your child's doctors and nurses. Your knowledge and expertise about your child are very valuable and will help the palliative care team develop the best treatment plan for your child.
- Palliative care can help improve the quality of time with your child while he or she is in the hospital. It can also help you and your family deal with the loss of your child if death occurs.
- Palliative care is about making your child and family comfortable.

Who Can Receive Palliative Care?

Any child who is very ill and not responding to medical treatments can receive palliative care. Palliative care is also good for children who have complex medical problems that could result in shortened life expectancy.

When Can a Child Receive Palliative Care?

- Palliative care can be given to a child whenever a life-threatening or life-limiting condition is diagnosed.
- Palliative care can be given along with usual medical treatments for any child with a life-threatening/life-limiting condition.
- Palliative care can be continued even if other medical treatment can no longer help cure your child's condition.

Who Provides Palliative Care for My Child?

The palliative care team is a specially trained group of professionals including physicians, nurses, social workers, psychologists, child life specialists, teachers, clergy, and volunteers. These professionals will help identify and treat ongoing physical, psychological, social, emotional, and spiritual needs of your child and family.

What Services Does a Palliative Care Team Provide?

- The palliative care team can help your child by providing new or different medicines and treatments to relieve pain, anxiety, and other uncomfortable symptoms. This may allow your child to be more awake during the day to interact with family and friends. In some situations, your child may be moved to a different care area (possibly even home) to allow increased freedom, space, and access to family and friends.
- The palliative care team can further help you understand your child's condition, treatment options, and likely outcomes. The team can help to find specific goals that are just right for your child's care. The palliative care team can help communicate these goals to the other doctors and nurses caring for your child.
- The palliative care team can address grief and stress that families may feel when they have a very sick child by providing emotional and spiritual support.
- The palliative care team can help find resources in the community to provide support to you, your child, and your family. This may include information from local and national organizations, or meeting other families in your community through organized support groups.

- If your child is near death, the palliative care team can help you and your family spend meaningful time with your child and help you cope with the intense grief when your child dies.
- The palliative care team can help you find ways to celebrate and honor your child's life.

Does My Child Have To Stop Medical Treatment To Receive Palliative Care?

- You do not have to stop medical treatment for your child to receive palliative care services. Your child can receive various treatments aimed at curing the illness while also providing your child with comfort measures. The doctors, nurses, and palliative care specialists caring for your child can assist you in these decisions.
- You do not have to limit or withhold medical treatments or have a Do-Not-Resuscitate (DNR) order to receive palliative care services.

Resources

www.MyICUCare.org

ICU Issues & Answers from SCCM

- Participating in Care: What Questions Should I ask?
- Taking Care of Yourself While a Loved One is in the ICU
- Common Problems of Critical Illness
- What Are My Choices Regarding Life Support?
- Helpful Hospital Safety Tips
- Sepsis: What You Should Know
- Making Decisions About ICU Care
- When Your Child is Admitted to the Intensive Care Unit
- Making Decisions When Your Child is Very Sick
- Why Do ICU Patients Look and Act That Way?
- What Should I Expect After Leaving the ICU?
- Palliative Care for Children

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